Arkansas

Spinal Courier Vol. 2 No. 2 A Publication of the Arkansas State Spinal Cord Commission January, 1991

Commission Has a New Logo

Since its inception in 1975 the Spinal Cord Commission has not had a logo or symbol to identify it. Commission Chair Russell Patton has often discussed the merits of a symbol or logo that can be used to identify the agency without our (sometimes cumbersome) name. He decreed that during his tenure as chairperson of the Commission we would have a logo!

In October Executive Director Cheryl Vines began working with the DHS Office of Volunteerism to find a volunteer to develop the logo. Hal Naylor of the Office of Volunteerism contacted the Cranford Robinson Johnson and Wood firm and they agreed to donate their time to the project. Tom Steves and Robert Burnham were assigned to the project. They worked with Ms. Vines and the

Commission to develop concept reflecting the independence and positive image of people with spinal cord injuries. Robert Burnham then came up with three choices for the Commission to review and they selected our new logo at their last meeting.

The logo was "unveiled" on January 23, 1991 by Commission Chair Patton, Billie Ann Myers, Director of the Division of Volunteerism, and creator Robert Burham of Cranford Robinson Johnson and Wood.

The Commission extends their thanks to the Office of Volunteerism for their integral assistance and especially to Cranford Robinson Johnson and Wood for volunteering their time and expertise to make our idea a reality!

SPINAL CORD

Tournament Directors, Harry Vines, Coach of the Rollin' Razorbacks and Cheryl Vines of the Spinal Cord Commission have been working on this event for over a year and plan to make it the best Final Four yet.

The Rollin' Razorbacks are serving as hosts for the tournament and are working with key sponsors Worthen Banks of Arkansas, Paralyzed Veterans of America, Mountain Distributing/Coors Light, Continental Medical Systems, Arkansas Power and Light, Quickie Designs and the Spinal Cord Commission to put on the tournament.

Volunteers will be needed for a variety of tasks in preparation for and during the tournament. If you'd like to help out, please call Cheryl Vines at 324-9624.

Plan to be there and help us show the wheelchair basketball world how Arkansas calls the Hogs!

NWBA FINAL FOUR

Mark your calendars for March 22 and 23, 1991 and plan to be at Barton Coliseum in Little Rock to see the best wheelchair basketball teams in the U.S. compete!

The 43rd National Wheelchair Basketball Tournament will be held in Little Rock this year. One hundred sixty men's wheelchair basketball teams all over the U.S. are working this season to qualify for regional and sectional competition, ultimately to become one of the FINAL FOUR. Semifinal

games will be held on Friday March 22 at 7:00 and 9:00 p.m. and the Championship Game at 1:00 p.m. on Saturday, March 23.

In conjunction with the competition, the National Wheelchair Basketball Association will hold its annual meetings, social activities and educational sessions and will induct new members into the National Wheelchair Basketball Hall of Fame. The Holiday Inn West will serve as the headquarters for the tournament.

Arkansas Spinal Courier

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Cheryl L. Vines Executive Director

Thomas L. Farley Editor

Published in cooperation with the Paralyzed Veteran's Association of America, Spinal Cord Injury Education and Training Foundation.

BUCKLE UP!

Grant Marshall Honored



The Board of Advisors for the Outstanding Young Men of America awards program recently announced that Grant Marshall has been included in the 1989 edition of Outstanding Young Men of America.

Grant is an incomplete paraplegic due to spinal cord tumors. He resides in Magnolia and graduated from Southern Arkansas University with a degree in Radio Announcing and Broadcasting. He presently volunteers his services as announcer of SAU's athletic department for all football and basketball games.

The OYMA program is designed to honor and encourage exceptional young men between the ages of 21 and 40 who have distinguished themselves in many fields of endeavor, such as service to community, academic achievement, business advancement, cultural accomplishments and civic and political participation. Achievements in these areas are the result of dedication, responsibility and a drive for excellence.

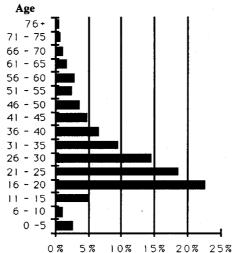
An Overview of Spinal Cord Injury in Arkansas

In May, 1990 the Arkansas Spinal Cord Commission had an active case load of 774 spinal cord injured individuals who were Arkansas residents at the time of their injury. An analysis of this group indicates the following preliminary findings:

Sex	Percent
Male	84
Female	16
Race White Non-white	78 22

Note: Blacks make up 93 percent of the non-whites.

Age at Injury



Level of Injury
Para 57
Quad 41
Unknown 2

Extent of Injury
Complete 43
Incomplete 45
Minimal 4

8

Do You Have a Pres (At time of interview	
Yes	18
No	73
Unknown	ç

Unknown

Have You Ever Been Hospitalized for Treatment of a Pressure		
Sore?	Percent	
Yes	26	
No	66	
Unknown	8	

Note: Paras and quads do not differ greatly from the above pressure sore data for all injuries.

Are You a Veteran?

Yes	20
No	76
Unknown	4

Education Level at Injury

Not school age	1
Elementary	16
H.S., no diploma	31
H.S. graduate	33
Some college	11
AA degree	1
Bachelor's degree	2
Post graduate degree	1
Unknown	4

Occupation at Injury

occupation at injury	
Laborer, operator	30
Service	9
Craft, repair	7
Farming, fishing	7
Technical, sales	6
Professional, manager	5
Unemployed	34
Unknown	2

If You Were Unemployed at Injury, What Activity Were You Engaged in? (N=249)

mgageu m: (M=249)	
Student	51
Homemaker	11
Retired	9
Infant, child	6
Other	23

Look for Part II in the next issue.

Wheelchair - Prison or Tool?

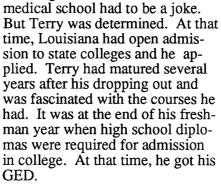
Terry Winkler, at 15 years of age was bored with school and convinced he could do just as well in life without it. He quit, got a job in the oil fields of Louisiana and was pleased with his income. He had the time and money to spend on his hobbies - cars and motorcycles. He also had time to spend with friends. In the predawn hours of March 6, 1971, Terry arrived at the home of a friend and reached in the glove box of his car for something. Finding what he wanted, he tossed the other contents, including a 22 caliber pistol, back. The gun accidentally went off and paralyzed him. He was only eighteen.

After one month in the hospital, Terry returned to his home with a borrowed wheelchair. For two years, he refused to purchase one, sure that he would again be able to walk. At the end of this time, he finally admitted that his paralysis was permanent. With his own wheelchair came a severe depression and thoughts of suicide. He had the support of his family, ministers and some friends, but nothing seemed to break through the darkness. Medical problems and twenty one surgical procedures added to his misery.

When he felt he was at the end of his rope, he picked up a Bible and began reading. Finding the verse in Psalms 1:3, he read "...like a tree that is firmly planted by streams of water which yields its fruit in season and its leaf does not wither and in whatever he does, he prospers." Suddenly this became his theme song. Terry began to see his way to a new future. He accepted himself as he was and found hope that things could be better. Determination he did not know he had emerged as he began to set goals - incredibly high goals. The wheelchair which he had seen as a prison before now became a tool. He saw it as his way of going where he wanted and succeeding at whatever he chose. At first, the chair was directing him, but now he saw himself in control - he was directing the chair.

Because Terry had been so closely involved with medical issues for several years, he felt a desire to

become a doctor himself. His Vocational Rehabilitation counselor was not at all encouraging. After all, this was a 22 year old man who had not finished high school. The thought of a high school dropout who was bored with school going to college and



In spite of obstacles and discouragement, Terry graduated from college and medical school and is now completing his residency in Physiatry (rehabilitation medicine) through the University of Arkansas Medical Center. 1990 has been a sharp contrast to that year when his world seemed to be falling apart. On October 14, he married a nurse he had been dating off and on for five years. With that marriage, he inherited eleven year old Nancy and fifteen year old Misty who are extremely proud to have him as their father. Then he received word that he, along with five other people in the United States, had been selected from among 10,000 nominees to receive

the President's Spirit Award for outstanding Americans. He didn't even know he had been nominated. Terry was honored, but he did not see himself as "outstanding" because he pursued a medical career from a wheelchair. He is not the "wheelchair doctor" as some people identify him, but he is a doctor who happens to be in a wheelchair. Terry describes himself as "someone's son, someone's

> twin brother. someone's husband," etc. "and least significant of all, a paraplegic."

While he sees himself as "just like anyone else," Dr. Winkler does recognize that there are problems with accessibility throughout the country. Because

make nondisabled people aware of the barriers and bring about needpeople in this country are disabled and it is becoming more important to make communities accessible to all people.

of this, he feels that people with a disability should work together to ed changes. He is convinced that these barriers exist not because people don't care, but because they have never had to enter a building, or park in a place that was inaccessible to them. Dr. Winkler states that 14% of the

Dr. Winkler admits that being in a wheelchair helps to develop rapport with patients. On the Progressive Care unit at Arkansas Children's Hospital, children are eager to see him coming down the hall. They can compare wheelchairs and communicate with their doctor almost at eye level. He seems to have time for them even when he's very busy. They are confident that he is a good doctor. But most of all, when they look at him, they know they can set goals and believe that a wheelchair is not an obstacle to success.



Terry Winkler, M.D.

DRIVING WITH A DISABILITY

I. Selecting a Car

This information on the selection of a car is for persons with disabilities who plan to drive a vehicle and transfer to and from it without assistance from others. In choosing a car, the wheelchair user must be able to safely get in and out of the vehicle, bring the wheelchair along, and safely operate the vehicle's controls. Therefore, selection requires the driver to review some basics facts before final purchase. Custom conversions are not discussed, but may include some of the items below.

Getting in and out-Transferring from the wheelchair to a car seat is easier with a two-door car due to strength, hand function, weather conditions, and type of car should be considered in choosing a storage method.

Two-door cars allow a user to store the wheelchair behind the front seat quickly and easily. Some persons lift the wheelchair over their laps and place it in the passenger's seat. Others get in on the passenger's side and pull the chair in the door behind them. A folding wheelchair or one with quick-disconnect wheels makes storage convenient inside the car. Securing the chair is important, so it will not interfere with driving.

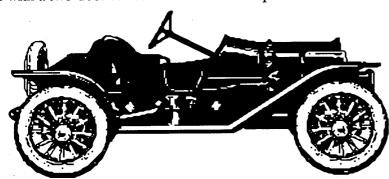
Life/storage units may be installed on the top of the car like a cartop considered for the vehicle. These devices often are not options for a driver with motion limitations.

- Automatic Transmissions and Power Brakes-These are required for all hand control systems.
- Power Steering-The hand control user is using arm strength to replace leg activity. Therefore, power steering is recommended to prevent arm fatigue. The van driver commonly has to have reduced or zero effort power steering to safely operate the vehicle.
- Cruise Control-This option relieves the driver of applying constant force and reduces arm fatigue.
- Power accessories Power door locks, mirrors, seats and windows are more than just conveniences for individuals with motion limitations.

2. Adapting a Car for Hand Controls

Throttle choices-Several types of accelerator controls are available for persons with movement limitations. Individuals who have use of one leg may find a left-footed accelerator pedal all that is needed. For those requiring full hand controls, pushing and/or pulling action as well as a twisting action similar to a motorcycle grip are available. Many systems can be installed for operation with the left hand or right hand, and most combine the throttle and brake into one control.

Choosing the right set of assistive driving controls should be based on the driver's physical characteristics as well as the model of car being used. Range of motion, arm and hand strength, and the ability to apply force to the controls for significant amounts of time (pushing, pulling, twisting or rotating



the usually larger door openings. Cars which have doors that open to a wide angle make the transfer easier too. For those who prefer to remain in the wheelchair or who cannot transfer independently, a van is a likely vehicle to buy. In this case, the van driver must be sure to purchase a reliable lift or ramp for access through the side or rear door of the van. It is important that your local van modification vendor be consulted on van types that are the easiest to modify, e.g., Ford E-150 series vans or Volkswagen Vanagon.

Storing the wheelchair-The wheelchair user has two ways to store the wheelchair while driving. Either store it on top of the car, or bring it into the passenger (or rear) seat area. The driver's physical

carrier. The unit's appearance, road noise produced, decreased fuel economy, and weather conditions should be taken into account before purchase.

Van drivers who will stay in the wheelchair while driving should be sure that proper wheelchair restraints (for both the chair and the driver) are utilized. The common brand names are E-Z Lock, CCI, Acroquip and A-straint. For those who transfer into the van's seat, concern should be with securing the wheelchair close by. Additional restraint systems should be installed for other wheelchair users to be transported.

Driving the car-Apart from the hand controls mentioned later, "optional" equipment should be



the hand control) must be considered. Many hand controls have special designs that allow for control. Experienced installers and prescribers are valuable advisors on individualizing these special designs.

Braking-In most vehicle emergencies, the body is thrust forward during braking. Therefore, the Veterans Administration only approves hand controls that apply the brakes when pushing forward. Power brakes enable individuals with good and arm functions to apply enough force to safely brake the vehicle with these controls. For drivers with limited movement or those who lack the necessary strength, additional power-assisted braking may also be installed.

Don't forget the parking or emergency brake when adapting the vehicle's braking system. The pedal or handle must be operated by the driver or an adaption must be made. Adapt the release lever, too. In many cases, van operators must use either linear or spool type electric emergency brakes.

Right and left side operation of the hand controls is often dictated by the shape of the dashboard. The dashboard's placement limits the distance the hand control can move. If a specific arm must be used, then car selection may be influenced as well.

3. Installation

Any purchase decision about hand controls must include consideration of who will install the device and maintain it. Manufacturers include installation instructions which can be used by a local mechanic. However, consistent results are obtained when the installer is factory trained, experienced in the problems of these installations, and installs hand controls on

a regular basis.

Once the decision has been made on which types of driving controls are needed, a decision must be made on who is the most desirable to perform the installation. First, start with a manufacturer installer at his facility. If not available, try for a distributor/installer of multiple brands of controls. Thirdly, find a certified installer. Lastly, depend on your local mechanic you know and trust.

Very often the decision between brands will dictate which installers you will be working with. Other factors to consider are convenience of distributor and installer location, provision for transportation to and from the service site, and an ability to service wheelchairs or other adaptive aids at the same location.

4. Maintenance and Service

Always keep the hand control manufacturer's warranties, guarantees, and owner's manual in the glove compartment. In this way, maintenance information is always available for any emergency that may arise.

Always follow the manufacturer's guidelines for maintenance and service of the hand controls. This includes checking bolt tightness, connections and lubrication of moving parts. By doing so, the service warranties usually remain in effect, as long as the service is done by a manufacturer approved repair person. If maintenance information is not included in the information provided to you at installation, ask for it from the installer and the manufacturer.

It will be easier to determine all the appropriate equipment if a trained equipment prescriber is involved in the entire process. This person will look at your functional skills and prescribe the most appropriate piece of equipment based on the latest technology available. The trained medical

professional can assist in the follow up or equipment installation by inspecting for proper fit as well as training with the equipment for safety and liability issues.

In some cases, the vocational rehabilitation agency in your area will require a trained prescriber and trainer to be involved in determining your equipment. This frequently is the easiest manner in which funding for adaption can be secured based on your vocational rehabilitation agency criteria. The purchase of the van or car is typically the responsibility of the client unless the client is a veteran.

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VENTILATOR USER NETWORK

Anyone who uses a ventilator full time or part time may be interested in subscribing (\$5.00 per year for individuals) to the International Ventilators Users Network News. This newsletter provides medical information, personal stories and practical suggestions that other ventilator users have found helpful. For further information, contact: Gazette International Networking Institute, 4502 Maryland Avenue, St. Louis, Missouri 63108.

Dr. McCluer is "Distinguished Clinician"

"What an exciting way to end a career" Shirley McCluer, M.D. commented with a smile when asked to describe how she felt about her recent honor. Dr. McCluer was referring to being selected as the recipient of the 1990 Distinguished Clinician Award from the American Academy of Physical Medicine and Rehabilitation at their meetings in Phoenix in October. This was indeed a well deserved award, reflecting Dr. McCluer's many years of dedicated service as a physiatrist (fis-e-at-rist), a specialist in physical medicine and rehabilitation. Truly a pioneer in her field, Dr. McCluer entered the rehab scene in 1955, when rehabilitation has only been "officially recognized" as a specialty eight years before. Specializing in spinal cord injury care (a "paraplegist") she has worked in some of the most prestigious programs in the country including the Sister Kenny Institute in Minneapolis, Spain Rehabilitation Center, in Birmingham and the Rusk Rehabilitation Center in Columbia, Missouri.

A Louisianian by birth, Dr. McCluer has "adopted" Arkansas, serving as the Medical Director at Hot Springs Rehabilitation Center from 1964 to 1969 and most recently since 1985 as a member of the faculty at University of Arkansas for Medical Sciences, Department of Rehabilitation Medicine, a program that she has helped develop, including serving as a physician at (then) Arkansas Rehabilitation Institute from 1985 to 1988. Though she plans to "really" retire from her University responsibilities this year (and dedicate more time to her favorite hobby, genealogy) she will remain as an active force with the Spinal Cord Commission as our Medical Director (since 1986).



Dr. McCluer decked out in her evening attire.

The Commission and staff congratulate Dr. McCluer on this well deserved honor and join the American Academy of Physical Medical and Rehabilitation in recognition of her many accomplishments.

Arkansas Spinal Cord Injury Association Established

by Gene Hamilton, ASCIA President

During the short time that the Arkansas Spinal Cord Injury Association has been in existence, we have come a long way. We organized in late May and elected officers to their first term on July 10, 1990 - just a few short months ago. We have worked with local cities and community leaders and successfully lobbied for the passage of ordinances in both Little Rock and North Little Rock to increase the fine for parking in handicapped spaces, without the proper decal, from \$25.00 to \$100.00. In addition, we worked to make polling places accessible or at least usable for the November elections. Our incorporation papers are complete, we have obtained our 501 c3 tax exemption and have secured a bulk mailing permit.

Committees have been appointed and are hard at work on a number of projects. We are presently surveying the public schools in the City of Little Rock and Pulaski County for accessibility. The Legislative Committee has had several meetings to educate elected officials and community leaders about SCI issues during the past few weeks. We are continuing to work on the Polling Places accessibility study project and hope to be completed this Spring. As we grow as an organization and more individuals become involved, these and other projects will be developed and implemented statewide. Yes, I would say that our members should be proud of our accomplishments over the past few months.

One of our most important projects is to increase our membership. I am asking that each of you make an effort to become involved and be active. There is much to be accomplished in our state and only we as citizens can do the job. I invite each of you to attend our meetings and become involved with one of our committees and be a part of these exciting changes. We meet at 6:30 p.m., the first Tuesday of each month, on the first floor at 1120 Marshall Street, in Little Rock.

For more information call 324-9628 days, and 758-2002 nights, or write the ASCIA P.O. Box 165258, Little Rock, Arkansas 72216.

Urological Care

by Shirley McCluer, M.D.

One of the most serious consequences of spinal cord injury is disturbance of normal bladder function with resulting damage to the kidneys. At the end of World War II (40-50 years ago), the leading cause of death following SCI was kidney failure. Since that time there has been progressive improvement due to the discovery of antibiotics to treat infection and to a better understanding of the causes of kidney failure and how to prevent it. The life expectancy has improved dramatically and kidney failure is no longer the most common cause of death.

The normal bladder is controlled entirely by the nervous system so that damage to any part of the spinal cord is likely to affect bladder function in some way. The most common problems are inability to empty the bladder and inability to prevent the bladder from emptying spontaneously. Both of these symptoms have a variety of specific causes which must be determined before management can be recommended.

Unfortunately there is no agreement even among experts on the ideal way to manage these problems. What is agreed is that:

- (1) Each patient must be followed carefully at frequent intervals for life. Serious complications can occur without causing symptoms until it is too late, so patients who wait until they are sick to see a doctor are taking unnecessary risks.
- (2) The follow-up should be done, whenever possible, by a physician with special experience and training in the management of spinal cord injuries. Even excellent urologists are not necessarily trained in or up-to-date on the latest information about SCI bladder care.

- (3) No management is perfect. Complications can occur even when apparently excellent recommendations are made and are followed carefully by the patient. However, each year this becomes less common as our knowledge improves.
- (4) Urological recommendations must take into consideration not only the results of tests on the bladder and kidneys, but the level of self-care, independence, life style of the patient, patient compliance with recommendations, availability of medical care, sex of the patient (females may require different management from males) and other factors. Patients who live in Little Rock will often be managed differently from patients in remote rural areas even by the same doctor.
- (5) Complications that can occur include bladder or kidney infections, bladder or kidney stones, loss of kidney function, incontinence (leakage of urine), etc. However, all of these can be prevented in most patients with good care.
- (6) Whether a patient is managed by intermittent catheterization, urethral catheter, suprapubic catheter, or external condom is less important than whether the method selected is correct for that patient.
- (7) Patients, care providers, and family members should make every effort to learn as much as they can about all aspects of bladder care in SCI and try to keep up-to-date on new developments. Don't be afraid to ask your doctor questions!

The Spinal Cord Commission is currently developing a series of "Fact Sheets" about different aspects of bladder function and management. If you are interested in more information, please contact your case manager.

SPINAL CORD DISABILITY FACT SHEETS NOW AVAILABLE

The Arkansas State Spinal Cord Commission, as a service of our new Education and Resource Center funded by the Paralyzed Veterans of America, is developing a number of Fact Sheets for individuals with spinal cord disabilities.

Fact Sheets are one page informational pamphets about specific spinal cord disability problems.

Twenty fact sheets will be developed over the next year and a half. Single copies of fact sheets are distributed free of charge and will be available from the ASSCC Education and Resource Center or from your case manager beginning February 4, 1991.

The following fact sheets have already been developed and are available:

- 1. Heterotopic Ossification in Spinal Cord Injured.
- 2. Common Problems associated with Catheters: Frequent Catheter Changes.
- 3. Common Problems associated with Catheters: Leakage around a Catheter.
- **4.** Heat Intolerence in Quadriplegics.
- **5.** Urological Management for Spinal Cord Injured: Foley Catheter.
- **6.** Skin Care in Spinal Cord Injured.
- 7. Intermittent Catheterization.

Got a topic that you would like to see developed into a Fact Sheet? Send your Fact Sheet suggestions and requests for Fact Sheets to Tom Farley, ASSCC, 1120 Marshall Street Suite 207, Little Rock, AR 72202 or call 324-9620.

Arkansas State Spinal Cord Commission Second Annual Spinal Cord Injury Conference

Little Rock, AR • June, 1991

Mark your calendar now! Additional details in the next issue.





The Second Annual 10k Run sponsored by United Medical for spina bifida was held at Camp Robinson on Saturday December 8, 1990. The brisk weather encouraged the participants to new personal best times.

Arkansas Spinal Courier
Arkansas State Spinal Cord Commission
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Commission Members:

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